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PEDS QL Multidimensional Fatigue Scale

Availability:	**For more information about this scale please follow this link.** **Author:** James W. Varni, (PROinformation@mapi-trust.org), Mapi Research Trust
Classification:	Exploratory for Mitochondrial Disease
Short Description of Instrument:	The PedsQL (Pediatric Quality of Life Inventory) is a modular instrument designed to measure health related quality of life (HRQOL) in children and adolescents ages 2-18 years. Composed of 18 items, the instrument possesses three subscales: general fatigue, sleep and rest fatigue, and cognitive fatigue. Both self-report and parental-report versions have been created to address issues of cross-informant discrepancies Specific population where scale is used (include age and criteria if applicable) Parent version: 2-18 years old. Child version: 5-18 years old, and adult
Scoring:	Likert scale used for scoring.
Rationale/Justification	Specific to Mitochondrial Disease **Strengths:** Fatigue is often a dominant symptom for mt disease pts; thus, a scale to record fatigue could have heuristic value for both pt and healthcare worker. The PedsQL MFS has been validated and applied extensively for many non-mt pediatric disorders in which chronic fatigue may manifest, including type 1 DM, rheumatological disease, obesity and cancer. The applicable age range is broad, being from 2-18yrs for the parent version and 5-adulthood for the child version. For young children, (ages 5-7), subjects can point to faces that match levels of severity/frequency of a given symptom. There is a corresponding parent report for each pediatric age range beyond 4yrs; from 2-4yrs, only the parents are queried. Each survey is brief and should take, at most, a few minutes for either parent or child to complete. Surveys are scored using a Likert scale from 0-4 in most cases. **Weaknesses:** The age range excludes pts <2yrs. However, many mt disease pt show signs c/w fatigue (weakness, floppiness, etc) before age 2 and many interventional trials would likely seek to enroll pts as early as possible to intervene before significant, irreversible damage occurs. Most, if not all, the age-dependent scales depend on a child with cognitive abilities greater than are present in many or most mt disease pts. The scale relies on recall over a 1 or 4 week period, which can lead to recall errors and is discouraged by the FDA in designing tools used as outcome measures in RCTs. I consider these last 2 issues to be the major limitations of the survey, viz applicability to mt disease

	pts. Limitations 1.) Age range doesn't extend below 2 yrs; however, many mt disease pts are diagnosed <2yrs of age and most interventional trials would likely seek to enroll pts as early as possible to intervene before significant, irreversible damage; 2.) Domains queried too limited and do not address major S/S common to mt pts, e.g., seizures, neurocognitive deficits and GI/neuromuscular complications; 3.) Scale implicitly relies on greater cognitive capacity than present in many/most mt disease children; 4.) Scale relies on recall over week-month, however, FDA discourages such scales b/o of recall errors 5.) Validated in a variety of pediatric diseases areas and effective across a large age range. Fatigue is a common complaint for patients with mitochondrial disease.
References:	Pediatr Diabetes. 2009 Aug;10(5):321-8. doi: 10.1111/j.1399-5448.2008.00482.x. Epub 2008 Nov 20. The PedsQL Multidimensional Fatigue Scale in type 1 diabetes: feasibility, reliability, and validity. Varni JW1, Limbers CA, Bryant WP, Wilson DP. Qual Life Res. 2008 Feb;17(1):105-14. Epub 2007 Nov 20. The PedsQL Multidimensional Fatigue Scale in young adults: feasibility, reliability and validity in a University student population. Varni JW1, Limbers CA. J Rheumatol. 2004 Dec;31(12):2494-500. The PedsQL Multidimensional Fatigue Scale in pediatric rheumatology: reliability and validity. Varni JW1, Burwinkle TM, Szer IS. Cancer. 2002 Apr 1;94(7):2090-106. The PedsQL in pediatric cancer: reliability and validity of the Pediatric Quality of Life Inventory Generic Core Scales, Multidimensional Fatigue Scale, and Cancer Module. Varni JW1, Burwinkle TM, Katz ER, Meeske K, Dickinson P. Int J Pediatr Obes. 2010;5(1):34-42. doi: 10.3109/17477160903111706. The PedsQL multidimensional fatigue scale in pediatric obesity: feasibility, reliability and validity. Varni JW1, Limbers CA, Bryant WP, Wilson DP. Qual Life Res. 2011 Sep;20(7):1103-8. doi: 10.1007/s11136-010-9836-9. Epub 2011 Jan 19. Fatigue in children: reliability and validity of the Dutch PedsQL™ Multidimensional Fatigue Scale. Gordijn M1, Cremers EM, Kaspers GJ, Gemke RJ. Pediatr Blood Cancer. 2014 Jan;61(1):171-7. doi: 10.1002/pbc.24776. Epub 2013 Sep 13. PedsQL™ Multidimensional Fatigue Scale in sickle cell disease:

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